

Ethical and Methodological Issues in HIV/Aids Social Science Research

Abstract

As a mainly sexually transmitted infection, HIV/Aids basically takes advantage of how we live our sexuality. Since biomedical research has so far not been able to provide a cure or vaccine, the only option we are left with is to change the behaviours that enable HIV/Aids to spread. To do so, however, we first need reliable data on the behavioural aspects of the HIV/Aids pandemic. Unfortunately this has proved challenging in Africa due to the fact that sex, in many African communities, is a hidden issue and is considered taboo to discuss openly. The question then is: how can we successfully – and ethically – collect this data despite the reluctance of people to discuss sex-related issues honestly and openly? This paper explores the ethical and methodological considerations of conducting research on the sexual aspects of HIV/Aids in the African context.

Introduction

As is well known HIV/Aids is mainly transmitted through unprotected sexual intercourse. In the absence of a cure or vaccine, changes in sexual behaviour are therefore the only effective means of slowing the spread of the virus (Auerbach 2001; Aggleton *et al.* 1994; Pool 1997). Promoting such changes requires interventions that take into account the complex interplay between gender, age and cultural context on the one hand, and HIV risk on the other. To develop effective interventions it is vital to improve our understanding of how cultural beliefs and practices and institutional structures influence how people and communities utilise prevention and care services. We also need to know more about the relative effectiveness of individual, behaviour-change interventions compared to community-based interventions. These goals can only be accomplished through social science research on HIV/Aids-related issues in society. This research should focus on how people's ideas about HIV/Aids affect their sexual behaviour and how the larger social, cultural and economic contexts affect both people's ideas and their behaviour.

It is clear to social scientists which areas need their attention. However there are two key methodological issues what are not yet clear. The first is how to manage the relationship between social science research and ongoing biomedical research (NIH 2000). The second concerns the methods that are appropriate for sampling and collecting data, given that open discussion of sex is generally taboo in the African context (Bailey *et al.* 2002; Auerbach 2001; Tyn-

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dall *et al.* 1994). These two issues are the main concerns of this short paper.

Ethical Issues and Social-Science Research on HIV/Aids

Social science research on HIV/Aids falls within the framework of the 1979 Belmont Report on the ethical principles and guidelines for the protection of human subjects of biomedical and behavioural research (NIH 2000). The report was a response to previous mistreatment and disrespect of human participants in research. Three famous examples will suffice to illustrate the issues. The first and most talked-about were the Nazi medical war crimes when Nazi physicians conducted harmful and degrading experiments on unwilling human participants. The experiments were performed on concentration camp prisoners and included such practices as injecting subjects with gasoline and live viruses, immersing subjects in ice water and forcing them to ingest poison. A second famous case was the Tuskegee Syphilis Study which was conducted from the 1930s up to 1972. In this study African-American men were used to study the natural history of untreated syphilis. The participants were recruited without informed consent and in fact were misinformed that some of the research procedures, such as spinal taps, were free medical treatments. Even after penicillin was found in the 1940s to be effective in treating syphilis, the men

were neither treated with penicillin nor informed about it. A third notorious example was the Jewish Chronic Disease Hospital Study of 1963, which sought to understand whether the body's inability to reject cancer cells was due to cancer or debilitation. This study involved the injection of live cancer cells into patients with various chronic debilitating diseases. Their consent had been given orally, but the injection of cancer cells was not discussed (because the researchers felt it would frighten them!) and in any case their consent was not documented. These and other cases showing serious disrespect for subjects' dignity and human rights led the Belmont Report to develop three fundamental ethical principles for future research: respect for persons, beneficence and justice.

The principle of respect for persons directs researchers to treat individuals as autonomous agents capable of thinking for themselves and making choices. To respect their autonomy is to respect their considered choices and refrain from obstructing their actions. Accordingly prospective research participants must be given ample time and all the necessary information to decide whether or not to participate in a study. Persons with diminished autonomy, such as children, prisoners and the mentally ill or the mentally challenged, require additional protection because they cannot make informed decisions. In these cases the person must be given as much opportunity to choose as he or she is capable of before seeking a mandate from parents or legal guardians. The principle of beneficence obligates the researcher to maximise the possible benefits for research subjects while minimising the possible harm. The challenge here is to decide when it is justifiable to seek cer-

tain benefits despite the risks involved. Balancing societal risks and benefits is also an important consideration, given that the goal of any research is to benefit society. The principle of justice requires researchers to distribute risks and benefits fairly and without bias. Consequently, unless there is a clear justification, research should not involve persons who are unlikely to benefit from subsequent application of the research.

How does social science research on HIV/Aids fit into this framework? Subjects participating in HIV/Aids-related studies are likely to be people infected or affected by HIV/Aids. These people are already hurt physically or psychologically, and are often desperate for help. Therefore they may agree to anything, not because they have made a truly free and informed choice, but merely because they think or hope that the research will help them. Moreover the study will probably involve sensitive personal information on their HIV status and social networks which, if not kept confidential, could cause them discrimination or other harm. Any proposed social science research on HIV/Aids therefore should first undergo an ethical review by an independent body to ensure that research methodologies adhere to the ethical principles of respect for persons, beneficence and justice.

Sampling and Data-Collection Methods

Since HIV/Aids is mainly a sexually transmitted, the behavioural issues surrounding it can be very difficult for research subjects to discuss openly and honestly. Sex and sexuality are delicate and hidden issues in many African cultures, and research into sexual beliefs and practices has to be carried out in a socially acceptable manner (Pool 1997; Tyndall *et al.* 1994; Schoepf 1993). Highly tactful and creative methods need to be used in gathering data. No ready-made research methods can be applied to all situations and all social phenomena when studying of the social and cultural aspects HIV/Aids (Auerbach 2001; Standing 1992). Therefore multiple instruments are generally used. However they still need to be adapted to the specific situation and culture under investigation. This requires creativity and innovation on the part of researchers.

In Africa people infected or affected by HIV/Aids often hide their predicament even from close friends and family members, as there is a great deal of stigma

associated with the disease in most communities (Shaw *et al.* 1996; Aggleton *et al.* 1994; Hendricks *et al.* 1992). Consequently sampling people infected or affected by HIV/Aids is a tricky exercise, especially if they are the main subjects of study. The most viable sampling method is snowball sampling. This method is often used when the desired sample characteristics are rare, hidden or hard to reach (Nigel 2001; Faugier and Sargeant 1997; Vogt 1999). Snowball sampling relies on referrals from initial subjects to identify additional subjects. Although it poses a number of methodological problems in terms of representativeness and sampling principles, it is nonetheless the most viable method in these circumstances, especially when no rigorous statistics are required from the analysis of the data collected. Data collection on the non-biomedical aspects of HIV/Aids also needs to borrow heavily from anthropological methods designed to elicit sensitive information tactfully (Pool 1997). Although formal interviews using questionnaires can be used, these may not yield as much information as more interactive qualitative conversations (Auerbach 2001; Standing 1992). Thus social science research on HIV/Aids would benefit greatly from methods such as participant observation, narratives, life histories, ordinary conversation and focus group discussions in conjunction, if need be, with more conventional methods such as questionnaires.

Participant observation is a basic anthropological research technique (Spradley 1979; Pool 1997). In this method the researcher joins the group being studied and observes while participating in the group's day-to-day activities. In this way the researcher gets first-hand data on the issues he or she is interested in. This method is based on the assumption that relevant and interesting information, particularly on topics that are delicate, taboo or hidden, is more likely to surface in an informal, participatory context than in a formal interview setting (Pool 1997; Spradley 1979). On the downside participant observation is time-consuming. A researcher cannot expect to gather enough data in less than six months.

Narratives are a form of interview where the informant tells a story about some relevant aspect of his or her life rather than the researcher asking question which have been pre-defined as important (Pool 1997; Boulton 1994). Narratives are

particularly suitable for getting information on a specific event in the life of an informant. Thus the researcher might begin with a request such as 'tell me the story of your marriage and how it ended up in divorce' or 'tell me about how your first relationship developed.' Narrative interviews can also elicit more general information by a request such as 'tell me how marriages typically end up in divorce.' The narrative approach is highly suitable for studying HIV/Aids-related topics such as sexual relations, strategies for coping with the disease, family relations and so on.

Life histories, unlike narratives, elicit the story of a person's life or some highly significant part of it. According to Boulton (1994) life histories are particularly suitable for obtaining information on social change, especially how people perceive social change. They can therefore be an invaluable way of understanding how people's lifestyles have changed since 1983 when the first case of HIV/Aids was identified. Although life histories can never provide definite evidence of past behaviours and norms, they can be used to ascertain broad trends, especially if there is agreement among different people's stories.

Ordinary conversation is also an invaluable source of information on obscure and taboo issues. In ordinary conversation information is gathered from informal discussions about a topic (Auerbach 2001; Boulton 1994). There is no clear boundary between spontaneous conversation and more informal interview settings. There are two ways of gathering information from informal conversations. Researchers may either position themselves where they can overhear people's conversations or can intervene to provoke and steer discussion themselves or through a secretly appointed local resident.

Focus group discussion utilises a group of eight to ten selected people freely discussing a predetermined topic (Steward and Shamdasani 1990; Dawson *et al.* 1993; Morgan 1993). A moderator is needed to ensure that the discussants keep to the subject and that each of them has a more or less equal opportunity to air his or her views. Focus group discussions are a cost-effective and rapid way to collect data and are very representative as long as age and status factors are considered when selecting participants. If a focus group discussion is well moderated, it can generate a lot of reliable